

January 18, 2007
Chairperson Edith Clark
and Members of Human Services Appropriations Sub-Committee

Chairperson Clark and Members of the Committee, my name is Chris Smith and I live in Helena. Thank you for your time and the opportunity to speak today.

I am testifying today on behalf of my two and a half year old daughter Gracie who is on Intensive Services through Family Outreach.

Due to uterine fibroids Gracie was born three months early, weighing 1 pound, 13 ounces. In addition to low birth weight, Gracie was born with Down Syndrome and needed several complicated surgeries.

Gracie spent 12 months in Seattle Children's Hospital receiving the specialized care and surgeries she needed to survive. She came home in May 2005 with a tracheostomy tube and g-tube. She was on a bi-level pressure support machine and oxygen and was in need of at least 18 hours per day of nursing care.

After being home for 3 months Gracie lost her SSI due to our middle-income status. We were all of the sudden in a crisis situation, faced with \$22,000 per month in medical bills to keep Gracie at home and out of the hospital. We applied a second time for Intensive Services—having been denied the first time. And were very fortunate to get a slot, given there were about 40 children on the waiting list at the time.

The Intensive program has provided Gracie with the much needed services and Medicaid card that she would otherwise not qualify for. It ensures that Gracie gets the nursing care, specialized medical care, medical supplies, and occupational, physical, and speech therapies she needs.

Gracie is very high functioning and the intensive services are directly responsible for how well she is doing--without them Gracie would not be where she is today. After spending one year in a hospital bed, Gracie was not even sitting up or rolling over. Since coming home in May of 2005, Gracie has learned to sit up, crawl, and is walking with assistance. She is very happy, social and loves to play, color, and paint. She has learned over 50 signs and is using them to communicate with myself and her nurses. And Gracie is set to start pre-school when she turns three in March.

Without Intensive Services, we would have lost everything and been bankrupt. The waiver has allowed me, as a single parent, to maintain my position as Art Director at and accounting firm and stay an active tax payer, homeowner, and productive member of society. I know that Gracie will excel in school, graduate, become an active member of our community, and touch many lives and hearts along the way. She is an amazing little girl with an amazing attitude. She and other children like her deserve every chance and opportunity to have

productive, fulfilling lives and it starts and hinges on these children and families receiving these services.

I am very concerned if funding is not significantly increased for the Intensive, Part C, and General Fund Services. The impact would be devastating for Gracie and myself, and the many other middle-income families in need of services and waiting to get them. That is why I am asking you to please support the additional funding needed for these programs.

Thank you again for your time and help.

September 6, 2005
Brad Johnson
Medicaid Waiver Screening Committee

Dear Mr. Johnson,

My name is Chris Purcell-Smith. I am a fourth generation Helenan. I have worked in Montana most of my life, been a business owner and employer, taxpayer, and community supporter. I am writing this letter because I find myself in a crisis situation needing assistance for my daughter from the State of Montana.

My daughter Gracie was born on March 21, 2004. Due to uterine fibroids she was born three months early, weighing 1 pound, 13 ounces. In addition to her low birth weight, Gracie was born with Down Syndrome, duodenal atresia (blocked intestine), and Tracheal Esophageal Fistula (esophagus that was not connected and attached to the airway). Nine days after Gracie was born in Great Falls, she and I were flown to Seattle where we would spend 12 out of 15 months at Childrens Hospital receiving the specialized care and surgeries she needed to survive.

Gracie had four surgeries leading to a successful repair of her intestine and esophagus. However, Gracie's health care needs changed significantly March 16, 2005 when she received a tracheostomy tube to get her through the healing of an upper airway surgery. Initially, the tube was to come out after a few weeks, but by putting the tube in it unmasked a problem with her lower airway. She was diagnosed with Tracheal Malacia, a floppy airway, and was unable to come off of the ventilator support after the surgery. We found out at this time that she would be going home with a tracheostomy tube, a bipap pressure support machine, oxygen, feeding pump, and nursing care.

The staff at Children's Hospital worked very hard for two months to get Gracie and I home. We arrived home on May 20, 2005. When we got home our insurance company, New West Health Services, covered the first 40 days of nursing and the first \$3,000 in durable medical equipment according to our policy. After the insurance resources were used up for the year, and all of our appeals denied, Gracie's SSI Medicaid kicked in as the secondary funding source. It wasn't until we had to requalify for SSI in July that we found out we were no longer eligible for SSI and therefore would also lose Medicaid on August 31, 2005. Apparently, as long as Gracie was in the hospital SSI did not take into account our income. When Gracie and I were able to come home that changed. They were now looking at our household income, which was too high according to their resource limitations.

It is true that we are not at poverty level. We are a hard-working, middle-income family that lived comfortably with two salaries before Gracie's birth. However, since her birth we have gone from a two-income household, to a one-income household, with me having to resign from my job due to the length of time I had to spend in Seattle with Gracie. So, financially the last year and a half has been tight for us. In addition, the stress of the last year and a half has taken its toll on my marriage. My husband and I are now in the process of getting a divorce and I am preparing to become a single mother of a medically intensive, special needs child. I will be reentering the work force, but even as a working, single mother I will still not meet the financial requirements for SSI or Medicaid. It is for this reason that I am writing you.

I am now faced with about \$22,000 each month in medical bills to keep Gracie at home. This includes 18 hours a day of nursing; durable medical equipment rental; medical supplies for her tracheostomy tube, GJ tube, feeding pump, BiPap pressure support machine, circuit, and humidification; occupational therapy (OT), physical therapy (PT), speech therapy (ST); prescriptions; and oxygen. I don't know of any middle-income family, let alone single mother that could possibly carry that financial load for any length of time and I know I cannot.

Since we've been home Gracie has made tremendous progress medically and developmentally. She is becoming a happy, strong little girl with a somewhat normal existence. At home we are able to give her a schedule which includes play time, bath time, dogs, OT, PT, ST, walks in the stroller outside, swinging and going to parks, trips in the car—even though it may be to go to a doctor, high chair at dinner time, and a comfortable, quiet room to sleep in that is all her own. I truly believe if she were still in the hospital she would not be doing as well as she is today. That is why I am asking you to please consider Gracie for the Medicaid Waiver slot you have open, as I fear her having to be rehospitalized otherwise.

Thank you for your time and consideration.

Sincerely,
Chris Purcell-Smith



